

Long-Term Care Task Force Briefing Paper

Issue: The role of family and other unpaid caregivers and current programs that support them.

Description: Many elderly and individuals with disabilities rely on family and friends to provide support. This includes providing assistance with activities of daily living such as bathing, dressing, eating, providing transportation, handling finances of the elderly/disabled individual, preparing food, housekeeping, etc. By creating incentives to support such care or by paying for some of this care, governments may delay or prevent the elderly/disabled individual from becoming largely or wholly dependent on government funding sources to support their care. Support can include caregiver support groups, vouchers that provide caregivers flexibility in obtaining the services they need, and respite care, which allows another person or facility to temporarily take care of an individual with a disability so the person caring for them at home can take a break. Existing programs to support unpaid caregivers already in place in Washington include paying for respite care to support the usual unpaid caregiver through Medicaid home and community-based care waivers, the Division of Developmental Disabilities' Family Support and the Aging and Disability Services Administration's Family Caregiver Support Program targeted to adults age 60 and over.¹

Background: Most of the elderly as well as individuals with disabilities in Washington live in a family setting (see **Exhibit 1**). This suggests that these individuals may rely on others in the household for assistance in a variety of areas.

Exhibit 1. Living Arrangements for Specific Washington Populations, 2004

Living Arrangement	Elderly Individuals (+65 years old)		Individuals with a Disability		
	All Elderly Individuals	Elderly Individuals with No Disability	Elderly Individuals with a Disability	Non-Elderly Adults with a Disability	All Adults with a Disability
Lives Alone	197,108 (29.5%)	106,589 (26.2%)	90,519 (34.6%)	87,422 (17.4%)	177,941 (23.3%)
Living with Others	472,043 (70.5%)	300,769 (73.8%)	171,274 (65.4%)	415,029 (82.6%)	586,303 (76.7%)
Married Couple Family	376,507 (56.3%)	257,508 (63.2%)	118,999 (45.5%)	213,184 (42.4%)	332,183 (43.5%)
Parent Living with an Adult Child	28,649 (4.3%)	9,658 (2.4%)	18,991 (7.3%)	5,907 (1.2%)	24,898 (3.3%)
Adult Child Living with a Parent	413 (0.1%)	413 (0.1%)	0 (0.0%)	50,913 (10.1%)	50,913 (6.7%)
Living with Relatives Other than a Parent	46,019 (6.9%)	20,738 (5.1%)	25,281 (9.7%)	91,956 (18.3%)	117,237 (15.3%)
Living with Other than Relatives	20,455 (3.1%)	12,452 (3.1%)	8,003 (3.1%)	53,069 (10.6%)	61,072 (8.0%)
Total	669,151 (100.0%)	407,358 (100.0%)	261,793 (100.0%)	502,451 (100.0%)	764,244 (100.0%)

Note: Disability was defined as an individual with any disability.

Source: American Community Survey, 2004.

¹ Home and community-based waivers are authorized under Section 1915(c) of the Social Security Act and Title III-E of the Older Americans Act amended in 2000 established the National Family Caregiver Support Program.

A number of estimates attempt to assign an economic value to caregiving for Washington State. In 1997, caregiving for Washington State was estimated to be about \$4 billion². A recent estimate put the value of caregiving at \$5.4 billion in 2000 for the State of Washington.³

Exhibit 2 shows caregiving and care receiver characteristics of Washington relative to the United States.

Exhibit 2. Caregiver Statistics for Washington and the United States, 2000

	WA	US
Informal Caregivers		
# of Caregivers (millions)	0.6	27.2
Caregiving hours (millions)	611.2	29182.0
Value of Caregiving (millions)	\$5,385.1	\$257,096.0
% of Grandchildren living with grandparents 65+	2.7	4.4
Care Receivers		
% Pop. 21-64 years with disability	17.8	19.2
% Pop. 65+ with disability	42.3	41.9
% 65+ by type of disability		
Sensory	16.8	14.2
Physical	28.9	28.6
Self-care	9.4	9.5
Mental	11.3	10.8
Difficulty going outside home	18.8	20.4

Source: Feinberg, L.F., Newman, S.L., Gray, L. & Kolb, K.N. (2004, November) The state of the states in family caregiver support: A 50-state study. Family Caregiver Alliance, San Francisco, CA.
http://www.caregiver.org/caregiver/jsp/content/pdfs/state_profile_wa.pdf

In Washington, all seven home and community-based care waivers which cover older adults, younger adults with physical disabilities, those with traumatic brain injury, and those with developmental disabilities include respite care. In addition, in October 2004, the state embarked upon a cash and counseling program to further expand its efforts related to consumer-directed care in King County targeted to adults with disabilities and older individuals who require nursing facility level of care. Under this program, individuals can hire family members to provide services.

² Arno, P., Levine, C., Memmott M. (1999) "The Economic Value of Informal Caregiving,". United Hospital Fund.
http://www.uhfnyc.org/pubs-stories3220/pubs-stories_show.htm?doc_id=107857.

³ Arno P. S., & Mintz S. (2004). Prevalence and economic value of family caregiving state analysis 2000. Kensington, MD: National Family Caregivers Association.

Exhibit 3. Washington Family Caregiver Support Program

Administering State Agency	WA State Department of Social and Health Services
Availability	Statewide
Local Program Administrative Responsibility	AAA
Major Sources of Funding	State General Fund FY2003 Program Expenditures = \$631,652 <u>Note:</u> Services are free with the exception of respite which applies a sliding scale
Eligibility	<ul style="list-style-type: none"> • No caregiver age requirement • Care receiver age requirement, age 18+ • Functional status requirement: Functional disability including diagnosis of dementia or related disorder/requires supervision
Assessment	Program assesses both caregiver and care receiver Areas addressed by caregiver assessment include: <ul style="list-style-type: none"> • Ability of caregiver to provide care • Caregiver demographic information • Caregiver strain • Emergency plan • Need for education/training • Other
Services include	<ul style="list-style-type: none"> • Assistive technology • Consumer supplies • Education & training • Family consultation • Home modification/repairs • Homemaker/chore/personal care • Information & assistance • Legal and/or financial consultation • Respite care • Support groups • Transportation
Types of respite care offered (no respite cap)	<ul style="list-style-type: none"> • Adult day services • In-home • Overnight • Weekend/camp
Consumer direction option	<ul style="list-style-type: none"> • A voucher or budget for respite and/or Supplemental services • Families have a choice of respite providers

Source: The State of the States in Family Caregiver Support: A 50-State Study, November 2004, NCOA, Family Caregiver Alliance

The Division of Developmental Disabilities' Family Support Program supports families while caring for a family member with a developmental disability in their home. Some services families may receive are:

- Respite care to provide short-term intermittent relief for persons normally providing care;
- Transportation;
- Specialized aids or equipment; and
- Therapies not covered by another resource.

The National Family Caregiver Program funds states and Area Agencies on Aging (AAAs) to provide supportive services to family caregivers. Washington supplements the federal funding with state general revenue. Services in Washington include: assistive technology, consumer

supplies, education and training, family consultation, home modification/repairs, homemaker/chore/personal care, information and assistance, legal and/or financial consultation, respite care, support groups, and transportation.

In 2002, the Washington legislature enacted two bills related to caregiving. One (SSB 6426) which required the state to offer family and medical leave benefits beyond the federally prescribed minimum and requires employers to allow employees to use sick leave or other paid leave to care for a spouse, parent, child, parent-in-law or grandparent with a health condition. The second (SHB 1397) established a kinship caregivers working group that The Kinship drafted a report that developed and prioritized 23 recommendations related to financial needs, legal issues, social services and system change. The report is available at www.aasa.dshs.wa.gov/topics/caregiving/documents/kinshipcare.pdf. In 2003, Casey Family Programs funded two Kinship Navigator pilot programs for one year – one Navigator program in Yakima and the other in Seattle.

Potential Options: The Administration on Aging compiled summaries of “Promising Practices in the Field of Caregiving,” across the county, including:⁴

- Providing culturally-sensitive training and training materials for caregivers as well as care-receivers on a number of topics including injury prevention, actual care-taking (e.g., transfer skills), managing chronic illness, interacting more effectively with health professionals and healthcare system
- Developing wellness programs for caregivers
- Assessing the needs of family caregivers and care-receivers specifically in relation to end-of-life care issues
- Identifying and involving caregivers in discharge planning
- Developing and disseminating medication programs for caregivers and care-receivers to assist them in resolving disputes

A systematic review of the services available and policies of the existing programs might suggest changes to these programs that might improve the level of support available to Washington’s caregivers. One area for further consideration may be younger individuals becoming caregivers (e.g., teenagers) as this raises questions such as the appropriateness of younger caregivers to fill-in that role as well as the differences in support that this younger generation of caregivers might need in comparison to older caregivers.⁵ In the future, the availability of caregivers could be affected by family mobility and higher employment rates among women (often the primary caregiver) status of the caregiver.

⁴ http://www.aoa.gov/prof/aoaprof/caregiver/careprof/nfcsp_projects/nfcsp_projects.asp

⁵ National Alliance for Caregiving, United Hospital Fund, Young Caregivers in the U.S., Report of Findings, September 2005.